

Stem Cell Tourism and Public Education: The Missing Elements

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Stem cell tourism describes the Internet-based industry where in patients receive unproven stem cell interventions. To better inform the public, several organizations provide educational material on stem cell therapies and tourism; however, an assessment of the currently available resources reveals a lack of comprehensive information, suggesting that further efforts are needed.

“Stem cell tourism” refers to the online, direct-to-consumer advertised industry wherein patients travel to receive unproven stem-cell-based interventions. Although it is nearly impossible to accurately calculate the number of patients who have received an unproven stem cell intervention, many suspect this number to be in the tens of thousands or more. And despite frequent criticism from the scientific community, regulators, and professional organizations, the industry continues to flourish. Providers advertise to patients by underplaying risks, peddling hope, and attempting to stifle warnings. In addition to the problem of financial exploitation, the provision of unproven interventions has been associated with causing tremors, tumors, lesions, and death. The term “stem cell tourism” itself is misleading because it focuses on patient behavior and does not reflect the reality that patients do not always need to travel. In total, stem cell tourism remains a significant policy challenge.

Some debates about curbing unapproved stem cell interventions center on tightening regulations. And several policy and enforcement initiatives have had limited success, as evidenced by the closure of clinics, sanctioning of physicians, and prosecution of scientists for manufacturing and distributing unapproved interventions (Master et al., 2013; Zarzeczny et al., 2014). Another major policy approach has been to improve the information available to patients, thus ensuring that patients are well informed prior to deciding whether to undergo an unproven stem cell intervention (Zar-

zeczny and Caulfield, 2010; Levine and Wolf, 2012). Several organizations have invested significantly in public/patient education by developing handbooks on stem cell therapies and unproven interventions, including the International Society for Stem Cell Research's (ISSCR's) *A Closer Look* website (<http://www.closerlookatstemcells.org>). But to date, there has been no systematic assessment of the accessibility or comprehensiveness of publically available educational content—an examination necessary in order to begin to determine the effectiveness of public education on stem cell pseudomedicine.

Here, we discuss the content of web-based, educational material on unproven stem cell interventions and clinical translation. Because stem cell pseudomedicine is an Internet-based industry, it seems that patients and caregivers are likely to use the Internet to find information about stem cell treatments. Moreover, research tells us that the public increasingly turns to the Internet for information about science and health (Pew Research Center's Internet & American Life Project, 2011). In addition to information about stem cell treatments, patients may also seek general information about stem cell biology, clinical translation of stem cells, and ethical and policy issues. Patients may also turn to local, regional, state, national, or international patient advocacy groups related to their condition to seek information, especially when bombarded with positively enforced advertisements for stem cell therapies in the media (Zarzeczny et al., 2010). Therefore, in

order to assess the nature and quality of available Internet-based material, we evaluated the educational content of 175 scientific organizations and patient advocacy groups on stem cell science, ethics, and policy and the clinical translation of stem cells and unproven interventions. We expected that, while there is some educational information on stem cell science and regenerative medicine, there would be little information on unproven stem cell interventions.

Organizations and Their Scope

Through keyword searches using <http://www.google.ca>, we identified 25 scientific societies, 10 stem cell research networks, 15 funders, and 125 patient advocacy groups. We based the selection of advocacy groups on the top five diseases that motivated individuals to travel to receive stem cell interventions: multiple sclerosis (MS), cerebral palsy (CP), spinal cord injury (SCI), amyotrophic lateral sclerosis (ALS), and Parkinson's disease (PD) (25 each) (Zarzeczny et al., 2010; Rachul, 2011). Efforts were concentrated on patient advocacy groups because they are known to provide educational information on the latest clinical developments and patients seem likely to be aware of and visit the websites of such groups. We assured that each organization fit the description of a scientific society, research network, funder, or patient advocacy group. See our [Supplemental Information](#) for further details on how we evaluated the organizations.

Jurisdictional coverage of the scientific and patient advocacy groups was

Table 1. Comparison Educational Topics between Different Scientific and Patient Advocacy Groups

	Scientific Societies (%)	Research Networks (%)	Funders (%)	Patient Advocacy Groups (%)
Science	43	67	49	21
Ethics/Policy	27	53	22	13
Treatment/Unproven Stem Cell Interventions	9	39	12	12

determined and only a few had international (11%) scope. Most organizations had national (38%) or state/provincial (30%) coverage. Most scientific societies (56%) had an international scope and the majority of research networks (67%) and funders (53%) had national reach. Patient advocacy groups tended to have equal national or state/provincial coverage (36% and 37%, respectively). Overall, the organizations we identified represented a total of 33 different countries, most of which were US-based (44%), followed by those in by Canada (24%), Australia (9%), and the UK (7%).

Educational Content on Stem Cell Science, Ethics, and Policy

We examined websites for educational content on three topics: (1) stem cell science; (2) stem cell ethics and policy; and (3) stem cell treatments, clinical translation, and pseudomedicine.

Overall, scientific organizations had significantly more content about stem cell science than patient advocacy groups ($\chi^2 = 32.6$; $df = 5$, $N = 175$, $p < 0.001$) (Table 1). In addition, scientific organizations had more content on ethical and policy issues related to embryo and stem cell research, or human subjects research, than patient advocacy groups ($\chi^2 = 33.3$, $df = 6$, $N = 175$, $p < 0.001$). Specifically, we observed that research networks had more information compared to scientific societies and funders on stem cell science ($\chi^2 = 16.8$, $df = 10$, $N = 50$, $p = 0.079$) and on ethics and policy ($\chi^2 = 18.2$, $df = 12$, $N = 50$, $p = 0.109$) (Table 1). We also found that ALS patient advocacy groups had slightly more coverage than other advocacy groups and CP patient advocacy groups had the least content on science and ethics/policy, although differences were not statistically significant.

Given that most scientific organizations have a mandate to educate scien-

tists and the public on stem cell research, it was not surprising that 72% of scientific organizations had at least some web-based content. Similarly, it seemed appropriate that many scientific organizations posted information on one or more ethics-related topics (e.g., the moral status of human embryos) and outlined policy issues related to stem cell research because these discussions were the main focus of early policy debates. It is only relatively recently that there has been emphasis on policy issues associated with the translation of stem cell research (Caulfield et al., 2012). Still, less than half of the patient advocacy groups had any web-based educational content, and while their mandates may capture educating patients about the disease, they would not necessarily capture advances in stem cell research or the associated ethical/policy issues.

The Missing Elements: Stem Cell Clinical Translation and Unproven Interventions

In a previous study, we examined the content and outlined several elements to consider when developing educational material for patients and the public on stem cell treatments and pseudomedicine (Master et al., 2013):

- providing a description of the clinical translation process and the need for proper ethics and regulatory oversight to ensure safety and efficacy.
- illustrating differences between established stem cell therapies, legitimate clinical research, and pseudomedicine;
- describing hallmarks of clinics offering unproven interventions (e.g., using one type of stem cell to treat many diseases);
- explaining risks associated with unproven stem cell interventions;
- explaining different kinds of evidence and why some, i.e., patient testimonials, should not be given much weight; and

The last point is especially important to discuss because studies indicate that patients may not fully understand the regulatory pathway and may distrust their domestic research and regulatory establishments, considering them unresponsive to their needs (Rachul, 2011). The expectation that treatments are available in other countries could be spurred by media hype of medical breakthroughs in stem cell research and reinforced by advertisements from clinics and endorsements from people who have visited them. For these reasons, patient information should describe the clinical translation process in order to help address questions of why it might take so long to develop stem cell therapies (Master et al., 2013).

While organizations had some content on the science of stem cells, we were somewhat surprised to find that, overall, both scientific organizations (16%) and patient advocacy groups (12%) had equally little information on stem cell treatments, the clinical translation process, and stem cell pseudomedicine ($\chi^2 = 0.000$, $df = 1$, $N = 175$, $p = 0.566$). Almost a quarter of scientific organizations and even fewer patient advocacy groups defined the concept of stem cell pseudomedicine, and only a handful of both sets of organizations had educational material explaining the clinical translation process and the need for ethics and regulatory approval (Figure 1); of these, many discussed clinical translation outside the context of stem cell research, which was not differentiated during coding.

These results show that while scientific organizations had some content on stem cell science and less on ethics and policy, overall, both scientific organizations and patient advocacy groups had very little information on stem cell treatments and pseudomedicine.

A Realistic Outlook on Patient Education

Educating patients and caregivers, while valuable in its own right, seems unlikely to significantly alter the demand for

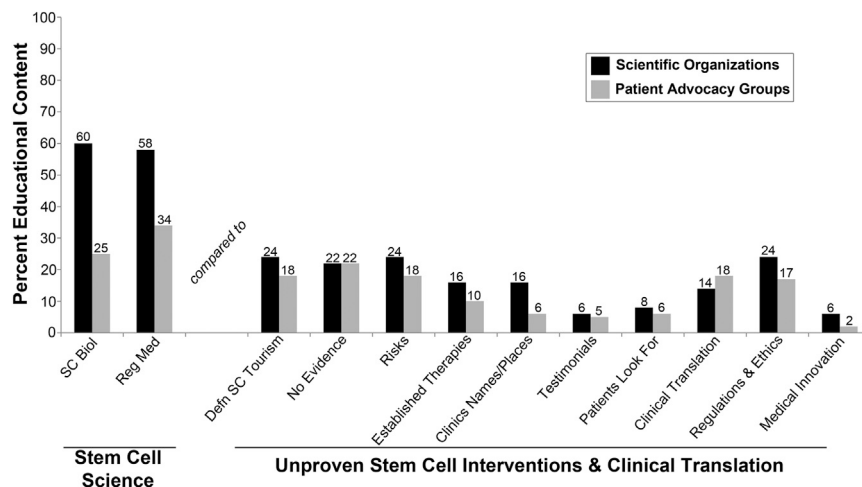


Figure 1. Percent Education Content on Stem Cell Tourism and Clinical Translation

From left to right, the *Stem Cell Science* category includes educational content on stem cell biology (SC Biol) and regenerative medicine (Reg Med). The *Unproven Stem Cell Interventions & Clinical Translation* category includes educational content: defining “stem cell tourism” (Defn SC Tourism), explaining that there is little or no evidence to offer many stem cell interventions (No Evidence), outlining the risks of unproven stem cell interventions (Risks), explaining that there are very few established stem cell therapies (Established Therapies), stating that patient testimonials are not the only means of demonstrating treatment efficacy (Testimonials), explaining what patients should look for when considering a stem cell intervention (Patients Look For), explaining the clinical translation process (Clinical Translation), explaining the need for regulatory and ethics oversight (Regulations & Ethics), and explaining the concept of medical innovation (Medical Innovation). Please see the codebook in [Supplemental Information](#) for further details of each subcategory.

unproven stem cell interventions. Evidence and expert advice are only one of many factors that influence decisions about these services. As noted by Alan Petersen, the educational “approach is underpinned by a rational actor model that assumes that individuals will rationally weigh up options in light of available information before deciding on the optimal decision. It overlooks the context in which identity is formed and hope assumes meaning” (Petersen et al., 2013). Still, educating patients will help them make more informed healthcare decisions irrespective of whether education is effective at dissuading patients from seeking unproven interventions (Master et al., 2013).

It is important to recognize what existing evidence tells us about the potentially limited impact of education. For example, a recent study found that educating parents with antivaccination attitudes did little to alter their vaccination behavior (Nyhan et al., 2014). While evidence-based health information refuting the vaccine/autism link regarding measles-mumps-rubella (MMR) vaccination made parents more informed, it failed to alter their decision to vaccinate their children.

Information in the form of images of children with MMR or a narrative about a child who had measles resulted in reinforcing beliefs in the serious side-effects of vaccines. Although the question about whether education changes the minds of patients to seek unproven stem cell interventions remains empirically unassessed, the above study suggests that patient information may be helpful at correcting some misinformation (e.g., debunking providers’ claims that stem cell interventions are risk free), but it may not dissuade patients from seeking unproven interventions. While today the unproven market of stem cell interventions for most diseases can be clearly distinguished, this separation is likely to become increasingly obscure as more stem cell research enters clinical phases. As a result, the blurring between unapproved but legitimate clinical research and more questionable unproven interventions will make it difficult for patients to navigate the clinical stem cell landscape. Thus, one of the goals of education on stem cell therapies is to help clarify concepts, explain how research leads to products, and help patients discern between legitimate research and fraudulent therapies. Arm-

ing patients with the right information is valuable irrespective of the decisions they make on whether to undergo an unproven stem cell intervention.

While a few organizations, such as the ISSCR, the National Stem Cell Foundation of Australia and Stem Cells Australia (<http://www.stemcellfoundation.net.au/patient-information/handbook>), Canada’s Stem Cell Network, the California Institute for Regenerative Medicine, and the UK MS Society (<http://www.mssociety.org.uk/ms-resources/stem-cell-therapies-and-ms-booklet>), have made significant efforts to develop education to help explain stem cell therapies to people seeking treatment, our data clearly shows an overall lack of web-based information. There appears to be a gap in basic information about stem cell research and therapy, the translation process, and stem cell pseudomedicine. Greater efforts are needed to develop educational materials, especially by patient advocacy groups because they are a trusted source of information for patients. While we have previously commented on the content of patient booklets (Master et al., 2013), these booklets need to also address limitations of the current system (e.g., the present need for more efficient regulatory pathways to handle stem cell interventions) and should avoid using preachy language or a finger-wagging tone. In addition, the booklet should be made simple and easy to read while maintaining scientific accuracy. Delivery of the message should adopt a neutral tone that is meant to provide unbiased information—attributes we recently attempted by developing a patient booklet based on our work (<http://www.amc.edu/stemcellbooklet>).

Many patients strive to gain an understanding of stem cell research and how it might be able to help them through self-directed learning, asking questions of their physicians (Levine and Wolf, 2012), and contacting patient advocacy groups. While our results indicate the need to develop more educational materials, uptake of the information requires effective delivery. In addition to physicians offering educational information to patients, patient advocacy groups can make a significant impact in delivering information to their constituency. Because many patient advocacy groups are volunteer run, they cannot be expected to

develop their own educational booklet on stem cell therapies. However, they can collaborate and help disseminate materials created by scientific and other professional organizations. Patient advocacy groups have an additional advantage over other professional organizations in that they are highly trusted by patients. Several criticisms have been made that scientists and other experts have “conflicts of interest” in that these professionals are biased toward their own agendas and do not sufficiently consider the needs of patients (Knoepfler, 2012). While these accusations may not rest on solid ground, they could deter the effective delivery of information to patients. As such, increased efforts are needed to not only develop educational material, but to also communicate with patient advocacy groups so they can provide a coordinated response, reaffirm the need for effective scientific research and regulatory oversight, and promote educational information on stem cell therapies to patients (Master and Sipp, 2013).

We need to be realistic in our expectations of education as a means to deter patients from seeking unproven interventions. Providing education is important if only to inform patients about stem cell therapies in order to help them better navigate the clinical landscape. Because there are a few reports of patients who are skeptical of provider practices (Rachul, 2011) or regret their decisions to undertake unproven stem cell interventions (Miles, 2008), it remains conceivable that education might help some recon-

sider options. It is important for the scientific, medical, ethics, and policy communities to continue to promote accurate patient and public information on stem cell research and tourism and to ensure that it is effectively disseminated to patients by working alongside patient advocacy groups. Coordinated efforts by governments, scientific organizations, the medical and ethics communities, and patient advocacy groups are needed if we are to realistically and significantly stifle the stem cell pseudomedicine industry.

SUPPLEMENTAL INFORMATION

Supplemental Information for this article includes additional details of experimental procedures and results and two tables and can be found with this article online at <http://dx.doi.org/10.1016/j.stem.2014.08.009>.

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WEB RESOURCES

The URLs for data presented herein are as follows:

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